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The Social Portrait of Families Upbringing Children with Cerebral Palsy

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ABSTRACT

Our study on the social and psychological portrait of a family raising children with cerebral palsy describes factors affecting the livelihoods of the family, participation of parents, other family members and society as a whole. The parents reflect to the socialization difficulties of their children in the form of excessive / insufficient parental care. Different family types and relationships as well as some aspects of the education of the disabled children are also analyzed. The role of the father is highlighted in the upbringing and education of children with cerebral palsy in the family.

Key words: social and psychological portrait of the family, Cerebral Palsy, family's activity, upbringing, the role of parents, subjective family wealth

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INTRODUCTION

Cerebral palsy (CP) is one of the leading causes in the structure of childhood disability. Annually, 200 out of 1000 newborns are born disabled, 70 of whom are diagnosed with CP. According to the statistics, the prevalence of CP in Kazakhstan increased over the past 10 years by 1.6 times from 44.6 to 73.6 per 100 thousand of population in 2006 and in 2017 respectively. The problem of CP received the greatest urgency in recent decades, since, according to some experts, there is a significant increase in the prevalence of CP. Nowadays, there are 626.7 thousand disabled people live in Kazakhstan, 11% of which are children. The birth and upbringing of a disabled child is a severe psychosocial stress for the parents, especially for the mother. It is the woman who is entrusted with the basic duties of raising and caring for a sick child, the life of the mother undergoes great changes caused by the birth of a disabled child [1,2].

Children with disabilities spend most of their time at home as they have limited health opportunities. The family is recognized as the most stable and significant social institution in a person's life, starting from the birth, including all periods of adaptation, integration into society, and even after the formation of the personality as an independent individual. The role of the family to teach the most important thing in the social environment which cannot be underestimated. No recent Kazakhstani studies focus on psychological environment for children with disabilities. At the same time, it is necessary to take into account that developing "mental health" involves active environment, society and directly interested people as parents, relatives, etc., who are actively participates in the social and cultural development of the individual human-being.

Our medical and sociological study was conducted in order to investigate particular needs of the families with CP children. So that, we studied data available at medical center "MaksatMed", established in 2011, where 2,650 cases with CP were admitted with the overall database of 68,000 patients admitted.

The aim of the study is to obtain social and psychological data on the family with CP children in order to substantiate further suggestions for improving their medical and social assistance.

MATERIALS AND METHODS

The study is based on detailed analysis of 418 cases of children with various forms of CP who were admitted from 2016 to 2019. The intensive indicators of the quantitative and qualitative structural composition of children in this category and their families are calculated. Social and hygienic characteristics of these families were studied by means of filling questionnaires; medical data was obtained by studying medical records of 185 families with a child with CP under the age of 18 years. Following methods were used: data extraction, expert evaluation method, analytical-graphic, analytical-statistical, sociological methods.

RESULTS AND DISCUSSION

The results of our study show that family structure and composition were as follows: complete, single-parent, large and foster families. Moreover, complete families raising children with CP in 63.1% cases were large (29.3%) with the total number of children varying from 3 to 7 people. It should be noted that social adaptation of the parents themselves had not been studied thoroughly. Earlier studies showed that at the age of 1, children with limited health opportunities spend similar period of time with mother as with their brothers and sisters, which greatly exceeds the time they spend with their father. The importance of the father's role in understanding and correcting developmental disorders is emphasized; although, it can be assumed it imposes additional duties and requires a lot of energy and time [3].

In 87% of cases, the mother was the main caregiver for the child with CP, so that, care and communication was mainly carried out in the form of a "mother and child" dyad. In 4.7%

cases, the main caregiver was the father. In 4,5% of cases the main caregivers were grandparents. in 3,8% the main caregivers were other relatives (sister, brother, etc.) and in 0,7% caregivers represented a foster family.

Many studies showed the importance of the family environment as a factor for the successful development of the child. Plethora of studies described the relationship between the mother and the child, thereby overlooking the role of the relationship with other family members, so that there is a need to develop individualized methods for the joint upbringing and education [4].

It is well-accepted that the father is involved in playing and organizing different games for children, whereas the mother is predominantly involved in care. The fathers support is especially relevant in families with disabled boys, where they can handle toys for useful training games. According to our data, there were more boys than girls amongst disabled children, 70,3% and 20.7% respectively. The father is less prone to hyper-care in raising children compared to the mother. This is especially often the case if the child is weakened, or has additional disorders. To help the parents, there were developed recommendations on psychocorrectional work for families with the disabled child [6, p. 1062-1065]. Parents should more often use exercises and games to develop their baby's emotions.

The family as an open system consists of opposing interactions. In particular, behavior and needs of family members, and especially of the disabled child, are also formed depending on the environment. It was also noted that physical and mental health indicators of such children positively correlated with social adaptation and maturation.

The integration of the family with a CP child into other systems faces many obstacles, which depends on the level of "permeability of the family system". It should be highlighted that, the state policy and society play an important role in this integration as it is the level at which the disability is dealt with and thereby further affects the relationship between the disabled child and its relatives, establishing communication and interaction as well as moral and psychological climate in the family [5].

Family composition and different factors play a role in the proper children development. Our study showed, that in our cohort single-parent families represented 36.9%. Single-parent families in their turn are characterized as more emotionally stunted, often disharmonious and large families (in 29.3% cases), surviving in inappropriate living conditions and unfavorable material support. Foster families (0.7% of cases from our study), in contrast, aimed to achievement, outward orientation. Finally, complete families represented 63.1% of cases, characterized by harmony.

Our sociological survey showed that, families with a disabled child know their legal rights to get free housing from the state. Nonetheless, the majority of respondents (59.7% of cases) claim that the whole organizational process and queuing is poorly managed. Although, 38.5% of the surveyed families have already managed to get housing on preferential terms. On the other hand, there were 1,6% respondents who were not interested in these opportunities. Furthermore, 47.4% of the families were incomplete (in 31.5% of them) and not employed due to inability to leave the child even for a short time. There were also families who live on children's allowances and allowances for children with disabilities (17.1% of cases). 44,3% of respondents indicated that the presence of the disabled child is not a criterion for employers. Furthermore, neither moral nor material aspects never be considered by them, for instance, assisting in having a part-time job with full wages as a support for these families.

In addition, it was indicated that housing and living conditions were not equipped for the disabled. Only 35% indicated that the entrances fully met the requirements and were convenient for the disabled.

Our research demonstrated that that children who was enabled to succeed with the program of specialized education, in many respects, were brought up in dysfunctional and often single-parent families. We assessed the effectiveness of the child's home environment indicator as the predictor of learning outcomes, which in turn included the child's development using toys, games, alphabet, etc. It should be underlined, that in 32,3% of enabled cases, the families refused conducting these strategies at home and thereby leading to poor progress.

The quality of care about the child's physical and mental health was also evaluated, in particular, tidiness, safety, emotional aspects, parents' love, adaptation to society, quality of preparation for school, lack of physical punishment. Several factors were observed such as mother's subjective well-being, psychological climate in the family, and interpersonal relations within the family, the organizational structure of the family, the quality of parental care and living conditions. These factors certainly correlated with a higher level of children's mental health and lower levels of stress.

Nonetheless, there were challenging issues, in which the family needed expert advice. So, for instance, 63.7% of respondents required free legal assistance. However, free consultations underlie long queuing's and thus challenging as there are time constraints associated with the need of constant care provision for the disabled child.

Furthermore, only 48,3% of the disabled children regularly receive spa treatments and physiotherapy. Probably, due to the fact that the caregivers not always follow the planned rehabilitation activities in time. Time deficit, lack of material resources, difficulties with transportation, as well as the inefficiency of these procedures were amongst main explanations from the caregivers. Nevertheless, 38,3% of the respondents noted a very good level of support from the social welfare bodies and charitable foundations; furthermore, the families were pleased with establishing centers for the disabled children with the help of local authorities and state bodies. According to the survey, children with CP require assistance with speech therapist - 13.7%, psychologist - 63.4%, defectologist - 14.8%, instructor of adaptive physical culture - 78.3%, social teacher - 80.5%. As can be seen from the Figure 1, the parents were interested in psychological help for themselves, for their further proper orientation in the moral, psychological and social development of the child's personality.

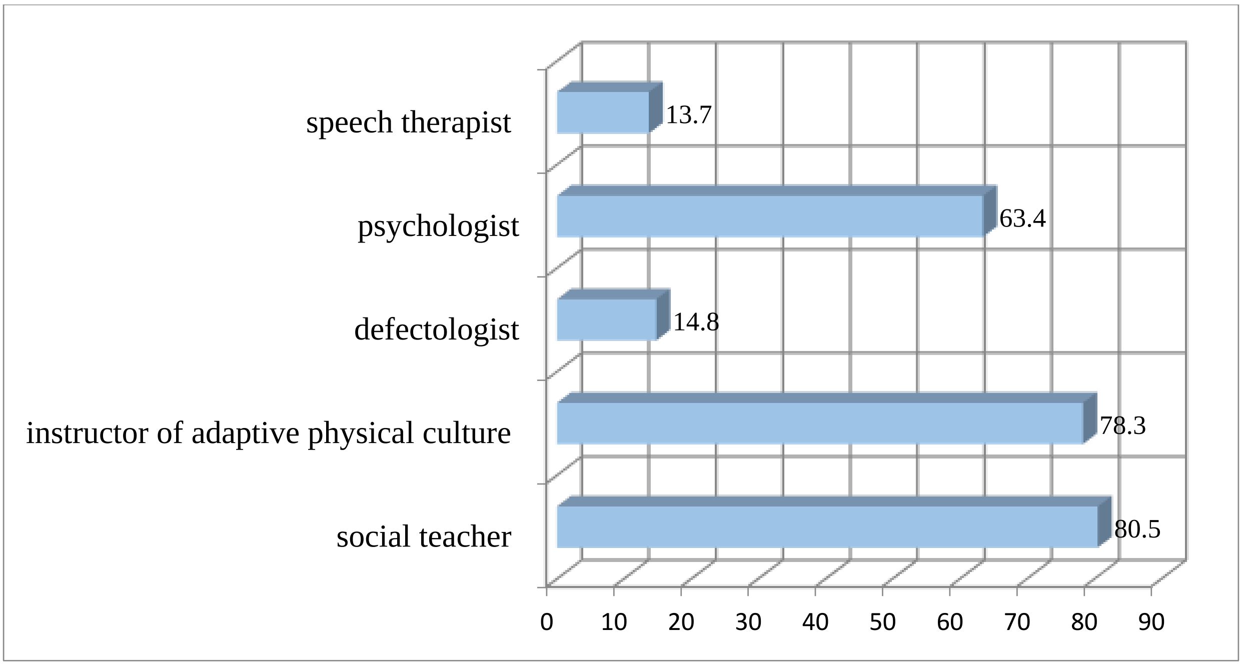

Figure 1: The children's needs in professional help and assistance

Proper exercising is crucial for motor skills. Regular physical exercising therapy underlies proper functioning of muscle-nervous tissue, followed by further development of motor reflexes.

Less than half of respondents (47.3% of cases) receive social pedagogical services. Among the reasons for the rejection of social services were shortly-timed training sessions (38.1%), poor level of professionalism of specialists (41.3%), too much of bureaucracy (20.6%).

Social taxi service was popular with 69.4% of respondents; whereas, the presence of a family's own car, the constant delays in social taxi, bureaucracy for getting this service- were the main reasons for refusing the service.

The study of stress associated with the birth of children with CP in the family, and its overcoming is an important but insufficiently studied problem. It is well known that any change in the external environment causes a change in the body, contributing to its greater susceptibility to the disease (Selie, 1983). The individual has less time to adapt to the situation, the more stressful the events are. This resulting in fact that for family members who are more or less involved in caring for a CP child at a certain stage, the adaptation processes will take different time.

We also studied the attendance of CP children of educational institutions. 24.3% of parents indicate that their children attend a specialized kindergarten. Moreover, 7.5% of children study at specialized secondary schools. 33,4% of the children prefer homeschooling. 34,8% of the children do not attend specialized educational institutions. Furthermore, it was found that there is a correlation between the dependence of the attendance of specialized educational institutions on the regularity of the rehabilitation activities (See Table 2).

Table 1: Attendance of specialized pre-schools and educational institutions and the regularity of rehabilitation activities (%)

Parameters	Adapted kindergarten	Adapted secondary school	Home-schooling	Do not attend
Regularly	85,5	88,2	31,6	20,5
Not regularly	14,5	11,8	68,4	79,5
Total	100	100	100	100

The quality of pre-school educational institutions and health organizations were also evaluated. It was found that 47.4% of the families were satisfied with the quality of service in preschool and educational institutions. 51.9% of cases were satisfied with health care organizations; on the contrast, there were 39.0% who were only partially satisfied.

CONCLUSION

Our study showed that in the majority of cases the disabled children being raised in incomplete families. The main factors affecting the livelihoods of the disabled children were absence of comfortable housing and lack of other facilities. In some families, the disabled child was the only one, as there was a fear for having another disabled child. The social worker is a key player as he represents a link between the family and the social support bodies in terms of identifying medical and social needs. The study showed that these children, living in the families, require social support according to their status. The obtained results on socio-hygienic status of the family can help to align needs and issues in order to develop proper policy as state support for the families raising children with CP.

REFERENCES

1. K.A. Dautova, G.A. Dikhanbaeva. The problem of families with children with disabilities. Bulletin of KazNMU №1. - 2018. - P.381-385.
2. T.K. Rakhypbekov, A.M. Elisinova, Yu.M. Semenova et al. Financial support for families raising disabled children in Kazakhstan and abroad. Science and Healthcare №1. - 2014. - P.8-11.
3. Mastyukova E. M., Moskovkina A. G. They are waiting for our help. Pedagogy to parents. - M .: Pedagogy, 1991. - P.105-117.
4. Shabenets E. A., Khatit F. R., Selmidis L. F. Factors of subjective well-being of mothers raising children with disabilities with cerebral palsy // Psychological and pedagogical features of the family of the XXI century: Coll. monograph Ulyanovsk: Zebra. - 2016. - § 6.4. - p. 404-419.
5. Mastyukova, E. M., Moskovkina, A. G. Family education of children with developmental disabilities: study guide for students. studies. institutions / Under. ed. V.I. Seliverstova. - M .: VLADOS, 2003.- 408c.